

## Patient Struggles for Philosophy

Art and literature can inform those of us who work in science and technology of the cultural, moral, and personal concerns that accompany the human diseases we study. Our need for a connection to humanity through art may be observed even at scientific meetings, when an attendee slips away to visit a gallery or to enjoy a musical performance. Moreover, it is not surprising to see colleagues reading abstracts and papers while traveling to a meeting and literature when returning home. These activities may be seen as diversions by some; nonetheless, they are diversions that inform. They address issues that scientific inquiry cannot penetrate: the personal and cultural contexts of our own lives and the lives of patients.

During *JID*'s "Year of the Patient," readers will have found cover artwork illustrating the concerns of patients. I have hoped that these contributions would remind us of the emotional and functional burdens that patients bear. This month readers will find a shift to the pen, with poetic contributions mostly from patients. One

poem, however, was written at my invitation by Marke Talley, a longtime friend, whose ability to describe our lives through words was revealed to me recently as we discussed my interest in the cultural context of skin diseases. It should not be necessary to describe these contributions further, because they speak their own messages.

Editors do not work in a vacuum but, rather, in a context. In addition to Elizabeth Blalock, I wish to thank my long-term associate and friend, Kenneth D. Shields, Professor of English Emeritus at Southern Methodist University, who helped guide the selection and editing of the poems that follow. Ken also reminded me of the literary gifts of John Updike, who lived with and then was freed from the burden of psoriasis. In the essay "At War with My Skin," Updike wrote, "The psoriatic struggles for philosophy, for thoughts that are more than skin deep. What could matter less than the integument a skeleton once wore?"

The contributions that follow offer a glimpse into realities of the sort that John Updike faced for most of his life. It mattered a great deal to him, it matters to our patients, and it matters to us.

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Editor

### Dreams of Psoriasis

After midnight, raining.  
Why no sleep? But I love rain.  
That damned itch on my ankle.  
Contact dermatitis? Did I wear polyester this week?  
Some new allergy?  
O please God, keep your arm around my shoulders and your  
hand over my mouth.  
Please, I have seen psoriasis!

I see in the darkness two friends who hide  
Not wanting you to see their scales, as if you don't know.  
One washes the counter after picking up samples  
Whenever he works in our laboratory.  
When he left they disinfected his chair,  
Just in case  
it was contagious.

But you who know how to find a cure  
Be sure to pray for skin and future, too.  
For our friends,  
We only hope  
It doesn't show, unless friends know.  
We only hope  
You will find  
A cure or even control.  
We only hope  
You will find your path.  
And we still hope.

Good hunting;  
May God bless you  
And keep an arm around your shoulders,  
A hand over your mouth.

—*Marke Talley*

### Psoriasis

Psoriasis has never been a term used to describe me.  
Security and comfort do not exist in my world.  
Obtaining intimacy and affection is not a reality.  
Receiving direct eye contact is a luxury.  
I have learned to leave swimming pools  
and gyms before being asked.  
Alone. No hope for husband and child.  
Society is my oppressor. You will be my liberator.  
I have never been accepted the way you have.  
Save me from the repression of my own shell.

—*Anonymous*

### My Hero

My Hero is not an actor or actress.  
My Hero is not an athlete.  
My Hero is not a great historian.

My Hero is someone with incredible  
strength and courage.  
My Hero is someone who inspires many.  
My Hero is someone who endures pain daily, and still manages  
to go on and even smile.  
My Hero is someone who to many may not seem beautiful,  
but to me is gorgeous.  
My Hero is someone who makes me laugh, makes me cry,  
and makes me proud every  
minute of every day.

My Hero is an EB Baby, an EB Child, and an EB Adult.

Dedicated to and inspired by my son, Jonathan Gionfriddo

—*Brenda Gionfriddo*  
Mom to Ashley (EB-free)  
and Jonathan (RDEB)

### Heat

When lilies burst in the sun,  
I open to their scent.  
When jasmine's fragrance finds  
me, I revel in it. My ears love  
cocky finches and the crickets'  
evening swell. But touch

tightens me; nerves that  
flicker towards a hand,  
ignite my skin like wires  
sparking down my back.

So what am I to do?  
I need a desert lover  
to want my orange dunes  
and find my wells  
in secret places.

—*Anne Kaier*